

*Gayle & Steven Temkin*

*In full support of Raised Bill No. 369*

**AN ACT CONCERNING AUTHORIZATION FOR THE USE OF FEEDING TUBES AND  
ANTIEPILEPTIC MEDICATIONS IN SCHOOL SETTINGS.**

Good morning -

Thank you for the opportunity to provide testimony in full support of  
Raised Bill 369.

Our six year old daughter Alyssa who is in first grade at Solomon  
Schechter Day School in West Hartford, has Glycogen Storage  
Disease (GSD) type Ia, a very rare metabolic disorder which means  
her body is missing a liver enzyme necessary to convert the stored  
form of sugar (glycogen) into the usable form (glucose).

Alyssa has a "mic-key button" (feeding tube) in her stomach. This is  
our life-saver. It's how we can feed Alyssa when she won't or can't  
drink her food by mouth-which is understandable because she is  
never hungry. It has also helped to keep her out of the hospital when  
she is sick because we can connect her to her feeding pump and  
know that we are doing our best to keep her safe.

Because Alyssa can not tolerate corn starch, she requires being fed  
every 90 minutes (1 hour and 30 minutes). Think about that....90  
minutes - that means stopping her while she is playing, that means  
interfering her while she is in school, that means making sure that  
when we are driving there is a place to stop, that means ALWAYS  
watching the clock, setting alarms and praying that for one reason or  
another that we haven't missed a feed.

None of this has ever caused Alyssa to want to slow down or be different. In fact she grows stronger with any obstacle placed in front of her. It was never a question in our mind that Alyssa would go to a mainstream school rather than a school for special needs students. Developmentally Alyssa is doing very well.

I on the other hand, am always focused on what's to come. It's become part of my internal makeup. I have no idea what kind of mother I'd be if Alyssa did not have GSD. The fact is, I'm scared all the time for Alyssa's health, I can't help it. Unlike other mothers who can fly out the door to run an errand with nothing more than their wallets, I can't leave the house without Alyssa's next drink-plus a few extras in case of spillage and all of her emergency supplies.

As i'm sure you can imagine, for my husband and I to be able to find comfort in knowing that we have TRAINED people who are qualified and capable to take care of our daughter is not an easy thing. But we have found comfort in those that we and Alyssa's medical team have trained. Trained does NOT mean that they have a degree in nursing, but instead means that they have taken the time to spend with us as a family unit, have taken the time to establish a relationship with Alyssa, and have taken the time to know whats best for our daughter in regard to her GSD. What does bring us comfort is knowing that Alyssa trusts the person sitting beside her every 90 minutes.

There is no way to expect any child (with or without a feeding tube) to accept a stranger to touch their body, or push food into them with a

tube and syringe. Alyssa did not ask for this disease, nor did she ask for her feeding tube, nor did she ask to have to be fed every 90 minutes. What Alyssa does ask is that Sarah feed her, or Jill feed her, or Stephie feed her, or someone that she is comfortable with feed her.

We need to remember that we can not look at the feeding tube as the issue at hand, but rather the child who happens to have the feeding tube!

But all that being said - I thank my lucky stars each and every day that I have my girls - Alyssa is ours for a reason.....ours being Steve and mine, and now yours -- She is sweet, compassionate, adorable, sensitive, caring and yummy child! We can almost guarantee that Alyssa will have an incredibly positive impact in your life and will change the world one day, she has already started!!!! We are so proud of our little girls....Alyssa is so powerful- as is her little sister Lily, who is a carrier but does not have this disease, they give us our needed strength!!

Alyssa still does not eat enough orally at the frequency and amount necessary to maintain her blood sugars, therefore it has been necessary to feed her through a feeding tube that was surgically implanted in her stomach. Over time Alyssa has been trying to drink her food, and we can only hope that the need for tube feeding decreases. For the time being, it is the primary way that Alyssa gets fed. We have been hopeful, that as Alyssa is in a classroom

environment, and sees other children eating, she would be encouraged to eat more. It is difficult to get Alyssa to eat orally because she is not that hungry since her stomach is being filled every 90 minutes.

Some people may say that school children who need to be tube fed have access to school nurses. However, due to the need to be available every 90 minutes and not be detained by another child's emergency, the school nurse could not be the one responsible to do the tube feedings. Alyssa's disease can cause her blood sugar levels to plunge dangerously low if she is not fed on time. The actual tube feeding is not a difficult medical procedure, but rather a necessity to avoid severe consequences to Alyssa's health.

Especially in these times, when governments are looking to save money, this Bill offers an opportunity to eliminate the requirement for a licensed nurse to perform duties that an aide can be taught to perform. We as parents deeply care for the health and well being of our child, and if we thought using an aide versus a licensed nurse would jeopardize Alyssa's health, then by no means would we support this bill. The truth of the matter is, rather than leaving Alyssa in the care of a nurse, we feel more comfortable leaving Alyssa at school in the care of someone like Sarah, who we know is very familiar with the use of the feeding tube thru her first hand experience of watching us feed Alyssa, who is very accepted by Alyssa, and who is very committed to taking the best care possible of our daughter.